



Welcome to the  
**FND-HBH COMMUNITY** 



# Our Core Values

HEALING • BELONGING • HOPE



## HEALING

We walk beside you as peers, offering support and understanding throughout your journey.



## BELONGING

We create a supportive community where every person's experience is acknowledged and valued.



## HOPE

We believe in a positive future and offer encouragement towards achieving your personal goals.

*These values guide everything we do.*



## About the Group

### About the FND-HBH Community

My name is Jordan, and I live with Functional Neurological Disorder (FND).

Through my own journey, I've experienced first-hand how isolating and confusing life with FND can be—especially when support is limited or difficult to access.

Because of this, both myself and my husband Skye set out with one clear purpose:

*To ensure that no one facing FND has to go through it alone.*

We created the FND-HBH Community as a safe, supportive space where people can come together, share their experiences, and feel understood.

This is a place where:

- You are listened to
- You are believed
- You are supported

No matter where you are on your journey.

We know that living with FND can be unpredictable and overwhelming, but together, we can build connection, understanding, and strength.

Whether you are newly diagnosed or have been living with FND for years—*you are welcome here.*

♥ *You are not alone. And you never have to be again.* ♥



# What to Expect from the Group

— A safe and supportive space for you —



## A Warm Welcome

Joining a new group can feel daunting—but you are not alone in that feeling. At FND-HBH, we aim to create a space where you feel comfortable, understood, and supported from the moment you arrive.



## There is No Pressure

- You do not have to speak if you don't want to
- You can simply listen
- You can share as much or as little as you feel comfortable with

This is your space.



## A Safe & Supportive Environment

Our group is built on:

- **Respect** • **Understanding** • **Kindness**

Everyone here is on their own journey, and we support each other without judgement.



## Confidentiality Matters

What is shared in the group stays in the group.

This helps create a safe space where *everyone* feels able to open up if they choose to.



## Shared Understanding

You are surrounded by people who:

- **Understand FND** • **Have lived experience** • **Know the challenges you face**

You do not need to explain yourself here.

— You Belong Here —

Whether you are newly diagnosed or have been living with FND for years—

♥ *you are welcome.* ♥



# Opening the Conversation

*Talking about FND with others*

## ♡ Starting the Conversation

It's okay to let others know about your FND.  
Sharing openly helps reduce stigma and brings awareness.

## ♡ What is FND?

Functional Neurological Disorder (FND) involves problems with how the brain and body send and receive signals, leading to real and often confusing physical and neurological symptoms.

## ✨ Ways to explain it

A good way to help others understand is to say that FND is a disorder where the brain has difficulty sending and receiving signals to the body—not because of damage, but rather due to a problem with the way the brain is working. Everyone's experience of FND is different, so it's important to explain what it's like for you personally.

## ♡ If people don't understand

Remember, it's okay if not everyone fully gets it. Encourage questions if you're comfortable, but you never have to justify what you're going through. Share resources or direct people to our group if they want to learn more.

## ♡ Remember

Talking about FND helps break the silence and shows that you are not alone. There are people who care and want to understand.



# Coping Tools & Grounding Techniques

*Finding calm in difficult moments*



## Why Coping Tools Matter

Living with FND can feel overwhelming at times—physically, mentally, and emotionally. Coping tools and grounding techniques can help bring you back to the present moment, reduce stress, and give you a sense of control when things feel difficult.

## Simple Grounding Techniques

### **1** Breathing Exercise

Slow your breathing:

- Inhale for 4 seconds
- Hold for 4 seconds
- Exhale for 4 seconds

Repeat until your body begins to feel calmer.

### **3** Body Awareness

Gently focus on your body:

- Notice your feet on the ground
- Feel your hands resting.
- Pay attention to your breathing.

This can help reconnect your mind and body.


### **2** 5-4-3-2-1 Technique

Focus on your surroundings:

- 5 things you can see
- 4 things you can feel
- 3 things you can hear
- 2 things you can smell
- 1 thing you can taste

This helps bring your mind back to the present.

### Coping Strategies

- Take breaks when needed
- Use pacing (*you're learning this* )
- Speak kindly to yourself
- Distract with calming activities (music, TV, reading)
- Reach out to someone you trust

*You are safe. You are supported. You will get through this. ✨*



# Finding Purpose

*Living with FND with meaning*

## Finding Purpose with FND

Living with FND can change many parts of your life—your routine, your plans, and sometimes even your sense of identity.

It's okay to grieve what has changed.

It's okay to feel lost at times.

*But your life still holds meaning. ♥ Your story still matters.*

## Purpose Looks Different Now

Purpose doesn't have to be something big or overwhelming.

- Getting through the day
- Taking care of yourself
- Supporting someone else
- Sharing your story
- Finding small moments of joy

*Purpose can be quiet.*

*Purpose can be gentle.*

*And that is enough.*

## You Still Have Purpose

Your worth is not defined by productivity.

You are not less because your life looks different.

You are still:

- Important
- Valued
- Needed

Exactly as you are.

## Redefining What Matters

Living with FND often teaches us to slow down and notice what truly matters.

- Connection
- Rest
- Understanding
- Small wins

These are not small things—they are powerful.

*Your life still has meaning. Even on the hardest days. ✨*



# Gentle Movement & Exercise

*Supporting your body with care*

## Why Movement Matters

With FND, movement can feel difficult or unpredictable.

But gentle, supported movement can help:

- Improve confidence in your body
- Maintain mobility
- Reduce stiffness
- Support overall wellbeing

*This isn't about pushing yourself—  
it's about working with your body.*

## Important Reminder

- Go at your own pace
- Stop if something doesn't feel right
- Rest when needed
- Small movements still count

## Seated Exercises (Low Mobility)

### 1 Leg Lifts (Seated)



- Sit comfortably in a chair
- Slowly lift one leg slightly off the ground
- Hold for a few seconds
- Lower gently

*Repeat on both sides.*

### 2 Ankle Rolls



- Lift your foot slightly
- Gently rotate your ankle in circles
- Switch direction

*Helps with circulation and stiffness.*

### 3 Arm Raises



- Sit or stand comfortably
- Slowly raise your arms in front of you
- Lower gently

*Use small movements if needed.*

### 4 Hand & Finger Movement



- Open and close your hands
- Gently stretch your fingers

*Good for coordination and tension.*

## Breathing & Body Awareness

### 5 Gentle Breathing



- Breathe in slowly  
• through your nose
- Breathe out slowly  
• through your mouth

*Helps relax the body and  
nervous system.*

## Listen to Your Body

Some days will feel easier than others—  
and that's okay.

**Even small movements are progress.**




*Every small movement  
is a step forward.*



# Easy Meal Ideas

Nourishing your body with less effort

## When Cooking Feels Difficult

Living with FND can make cooking feel overwhelming—especially on days when energy is low or standing for long periods isn't possible. 

This page is here to remind you:

- It's okay to keep things simple
- It's okay to take shortcuts
- You still deserve to eat well

## Low-Effort Meal Ideas (Seated Friendly)



### Quick & Simple

- Sandwiches or wraps
- Toast with toppings (beans, eggs, avocado)
- Crackers with cheese or spreads



### Minimal Cooking

- Microwave meals
- Instant noodles or soups
- Jacket potatoes (microwave or oven)



### No-Cook Options

- Yogurt with fruit
- Cereal or granola
- Pre-made salads
- Smoothies



### Easy Assembly Meals

- Pre-cooked chicken + *sallad*
- Pasta with ready-made sauce
- Rice + vegetables + *protein*



## Helpful Tips

- Sit while preparing food
- Use pre-cut or frozen ingredients
- Batch cook on better days (if possible)
- Keep easy snacks nearby



## Be Kind to Yourself

Eating something is always better than nothing.  
Your body needs fuel—even on the hard days.

*Simple meals are still good meals. +*



# My Safe Space Plan

— *Creating comfort when things feel overwhelming* —

## How I Know I Need My Safe Space

- I start to feel: \_\_\_\_\_
- My body feels: \_\_\_\_\_
- My thoughts become: \_\_\_\_\_

## What Helps Me Feel Safe

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## People I Can Reach Out To

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## My Go-To Coping Tools

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## What I Can Tell Myself

- “I am safe.”
- “This will pass.”
- “I can get through this.” \_\_\_\_\_

## My Comfort Plan

When I feel overwhelmed, I will: \_\_\_\_\_

\_\_\_\_\_

*You deserve to feel safe, supported, and in control. ✨*



# My Safe Space Plan

*Creating comfort when things feel overwhelming*

## How I Know I Need My Safe Space

- I start to feel: \_\_\_\_\_
- My body feels: \_\_\_\_\_
- My thoughts become: \_\_\_\_\_

## What Helps Me Feel Safe

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## People I Can Reach Out To

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## My Go-To Coping Tools

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## What I Can Tell Myself

- "I am safe."
- "This will pass."
- "I can get through this." \_\_\_\_\_

## My Comfort Plan

When I feel overwhelmed, I will: \_\_\_\_\_

*You deserve to feel safe, supported, and in control. ✨*



# What is Pacing?

— Understanding balance with FND —



## What is Pacing?

Pacing is about finding a balance between activity and rest.

When living with FND, it can be easy to do too much on a ‘good day’ and then feel the impact afterwards. Pacing helps to manage your energy in a way that supports your body rather than overwhelms it.



## Why is Pacing Important?

Without pacing, it's common to fall into a cycle of:

- Doing too much
- Experiencing a flare-up
- Needing longer recovery time
- Reduce flare-ups
- Improve consistency
- Support long-term progress



## The Boom & Bust Cycle

Many people with FND experience what's known as the *boom and bust* cycle. This is when you:

- Feel good → do too much (boom)
- Crash afterwards → need rest (bust)

Pacing helps break this cycle by encouraging steady, manageable activity.



## How to Practice Pacing

- Break tasks into smaller steps
- Take regular rest breaks
- Stop *before* you feel exhausted
- Spread activities throughout the day
- Be consistent, even on good days.

✦ *Slow and steady is still progress.* ✦



# My Pacing Task List

*Understanding my energy levels*



Use this page to understand how much energy different tasks take for you. Everyone's energy levels are different—this is about your body, not anyone else's. Over time, this can help you plan your day and avoid overdoing it.

## My Pacing Task List

Task	Energy Level (1–5)	Before (How I felt)	After (How I felt)	Notes
	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/>			

**Energy Scale**

1 = Very low energy  
*(easy task)*

2 = Slight effort

3 = Moderate effort

4 = High effort

5 = Very draining

**Examples**

- Showering
- Cooking
- Walking
- Socialising
- Cleaning
- Work tasks

## Reflection

What did I notice today?

---



---



---

Did anything take more energy than expected?

---



---



---

*Understanding your energy is the first step to managing it. ✨*





# TODAY'S SYMPTOMS

DATE:

\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
DAY / MONTH / YEAR



## WHAT I'M FEELING:

*(List your symptoms — physical, cognitive, emotional)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**SEVERITY LEVEL:** *(Circle one for each symptom)*



## TRIGGERS TODAY:

*(What made symptoms worse?)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## WINS / POSITIVES:

*(Any small victories today?)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## NOTES / EXTRA DETAILS:

*(Anything else to add?)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



**EVERY DAY MATTERS. YOU ARE NOT ALONE.**

*One step at a time.*



# TODAY'S SYMPTOMS

DATE:

/ /  
DAY / MONTH / YEAR



## WHAT I'M FEELING:

*(List your symptoms — physical, cognitive, emotional)*

---

---

---

**SEVERITY LEVEL:** *(Circle one for each symptom)*



## TRIGGERS TODAY:

*(What made symptoms worse?)*

---

---

---



## WINS / POSITIVES:

*(Any small victories today?)*

---

---

---



## NOTES / EXTRA DETAILS:

*(Anything else to add?)*

---

---

---

---



**EVERY DAY MATTERS. YOU ARE NOT ALONE.**

*One step at a time.*



# TODAY'S SYMPTOMS

DATE:

/ /  
DAY / MONTH / YEAR



## WHAT I'M FEELING:

*(List your symptoms — physical, cognitive, emotional)*

---

---

---

**SEVERITY LEVEL:** *(Circle one for each symptom)*



## TRIGGERS TODAY:

*(What made symptoms worse?)*

---

---

---



## WINS / POSITIVES:

*(Any small victories today?)*

---

---

---



## NOTES / EXTRA DETAILS:

*(Anything else to add?)*

---

---

---

---



**EVERY DAY MATTERS. YOU ARE NOT ALONE.**

*One step at a time.*



# TODAY'S SYMPTOMS

DATE:

\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
DAY / MONTH / YEAR



## WHAT I'M FEELING:

*(List your symptoms — physical, cognitive, emotional)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**SEVERITY LEVEL:** *(Circle one for each symptom)*



## TRIGGERS TODAY:

*(What made symptoms worse?)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## WINS / POSITIVES:

*(Any small victories today?)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## NOTES / EXTRA DETAILS:

*(Anything else to add?)*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



**EVERY DAY MATTERS. YOU ARE NOT ALONE.**

*One step at a time.*



# Triggers & Patterns

**Noted triggers:**

---

---

---

**Pattern I noticed:**

---

---

---

**How I responded:**

---

---

---

**What I learned:**

---

---

---



# Triggers & Patterns

**Noted triggers:**

---

---

---

**Pattern I noticed:**

---

---

---

**How I responded:**

---

---

---

**What I learned:**

---

---

---



# Triggers & Patterns

**Noted triggers:**

---

---

---

**Pattern I noticed:**

---

---

---

**How I responded:**

---

---

---

**What I learned:**

---

---

---



# Weekly Reflection

How has this week been for me?

---

---

---

What were my challenges?

---

---

---

A small win or positive moment:

---

---

---

One thing I want to improve:

---

---

---

Something I am grateful for this week:

---

---

---



# Weekly Reflection

How has this week been for me?

---

---

---

What were my challenges?

---

---

---

A small win or positive moment:

---

---

---

One thing I want to improve:

---

---

---

Something I am grateful for this week:

---

---

---



# Weekly Reflection

How has this week been for me?

---

---

---

What were my challenges?

---

---

---

A small win or positive moment:

---

---

---

One thing I want to improve:

---

---

---

Something I am grateful for this week:

---

---

---



## Stay Connected

*Join our community beyond the group*



### WhatsApp Group Chat



Stay connected with others in the FND-HBH community. Share experiences, ask questions, and support one another in a safe and understanding space.

### Our Social Media Pages



Follow us to stay updated, find helpful resources, and be part of a growing community that understands your journey.

### A Gentle Reminder

You are always welcome—whether you want to chat, read, or simply feel connected.



*+ Connection makes the journey a little easier. +*



Our close friend and fellow FND warrior  
**Helen** is also doing amazing work  
to help our community.

*You can follow and support her here:*

**FND Warriors UK**

**Helen on TikTok**





# Support & Important Contacts

Help when you need it most



## You Are Not Alone

If you are struggling, there are people and services available to support you. Reaching out can feel difficult—but help is always there.

### Emergency Support

Emergency Services: 999

NHS 111: 1111

(urgent medical help, non-emergency)

### Mental Health Support

Samaritans: 116 123 (24/7)

Shout (Text Support):  
Text SHOUT to 85258

Mind: 0300 123 3393

### FND & Neurological Support

FND Hope UK: [www.fndhope.org.uk](http://www.fndhope.org.uk)

### When Reaching Out Feels Hard

You don't have to explain everything

You can take your time

Even a small step is enough

### Local & Community Support

---

---

---

---

### My Personal Contacts

---

---

---

---

✦ There is always someone ready to listen. ✦





# A Final Message

From our community to you



## Before You Go

If you take one thing from this booklet, let it be this:

***You are not alone.***

## Your Journey Matters

Living with FND is not easy.

There will be good days and difficult ones.

But every step you take—no matter how small—is *progress*.

## You Are Part of Something

The FND-HBH Community was created so that no one has to face this alone.

You are now part of a space built on:

- Healing • Belonging • Hope

And that means something.

## On the Hard Days

Come back to these pages.

Take things one moment at a time.

Use the tools.

Reach out.

Be kind to yourself.

## Final Words

✦ *You are stronger than you feel.* ✦

✦ *You are supported more than you know.* ✦

*And you never have to go through this alone again.* ✦

— The FND-HBH Community



Thank you for being a part of the

**FND-HBH community** 

We're here with you every step of the way.